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WOMEN'S ILLNESS NARRATIVES: STORYTELLING AS ARTS-INFORMED INQUIRY

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Abstract

This article explores three narratives from South Asian Canadian immigrant women living with HIV, and how the project shifted from a conventional qualitative interview methodology toward an arts-informed narrative inquiry. Sharing my own story as an immigrant and refugee woman helped to establish trust and an emotive engagement with the women, making it easier for them to share their HIV-related experiences. Using a storytelling approach and Arthur W. Frank's illness perspectives (1995), which include restitution (getting well), chaos (hopelessness), and quest (transcendence) as a framework, can deepen understandings of their lived experience as immigrant and refugee women living with HIV.

Résumé

Cet article explore trois récits de femmes immigrantes canadiennes de l'Asie du Sud vivant avec le VIH et examine comment le projet s'est éloigné d'une méthodologie d'entrevue qualitative traditionnelle pour devenir une enquête narrative axée sur les arts. Partager mon propre récit comme femme immigrante et réfugiée a favorisé l'établissement de relations affectives et de confiance avec les femmes, ce qui a facilité le partage de leurs expériences associées au VIH. Utiliser comme cadre une approche axée sur le conte et les perspectives sur la maladie de Arthur W. Frank (1995), dont la restitution (la guérison), le chaos (le désespoir) et la quête (la transcendance), peut approfondir la compréhension de leur vécu comme femmes immigrantes et réfugiées vivant avec le VIH.

Background: From Data Gathering to Storytelling

This study began when I developed a collaborative relationship with the Alliance for South Asian AIDS Prevention (ASAAP), a community-based organization serving South Asian and Middle Eastern people living with HIV in the Greater Toronto Area (GTA). ASAAP is a gateway to these women who rarely have a voice in HIV research (Hawa, Underhill, Logie, & Loutfy, 2017; Kteily-Hawa, Islam, & Loutfy, 2018), despite South Asian women representing 3.5% of newly diagnosed HIV cases in Ontario in 2011, doubling to 7%

by 2015 (Ontario HIV Treatment Network, 2015). While the number of people contracting HIV has remained static at the global level since 2010 (UNAIDS, 2016), it is growing in Ontario and the GTA (Ontario HIV Treatment Network, 2015), especially among South Asian immigrant women. Over a period of seven months, I formed a partnership with ASAAP and we created an advisory committee to provide study support. The University of Toronto granted ethics approval. Sampling protocol included a combination of outreach efforts (Pernice, 1994) and snowball sampling. In-depth face-to-face, individual interviews were conducted with 12 self-identifying South Asian immigrant women living with HIV in the GTA; participants ranged in age from 28 to 50 years.

Originally, I had planned to interview each participant using a semi-structured interview guide. The transcript from the first interview was short and methodical and lacked flow; answering the interview questions did not help participants to share their lived experiences. A different approach was required. I realized that while it is really important for researchers to think carefully about how they create conditions for stories to be told, they must find ways for these stories to be heard. For me, that realization emerged in the process of interpreting the women's stories and reflecting on my own experiences as an immigrant and refugee. Starting with my own story initiated an emotive engagement or spark with the women, making it easier for them to share their HIV-related experiences. The conversation flowed more freely and their emotional engagement with their stories let them move through a process of critical reflection. Through telling their stories to me, these women got the chance to try to "*move beyond* a sharing of experience, to a fuller expression and shaping of *their* story in a way that makes sense and matters to *them*" (Eaves, 2014, p. 156). Some have been living with this disease for more than 15 years.

Narrative research entails recounting the individuals' personally meaningful stories and experiences in combination with the researcher's interpretation (Lindlof & Taylor, 2017). As I reflected on the data, I felt a connection to three stories because they resonated with my own lived experience as an immigrant and racialized woman. I could sense the restitution, chaos, and quest experienced by these South Asian immigrant women living with HIV, as these experiences are entangled and intertwined in my life. Sharing my own story with them created a carefully constructed connection, where the women felt more comfortable sharing their HIV experiences in the presence of an attentive and genuinely interested, emotionally engaged listener. This approach reflects feminist research methods, evident in the creation of a research atmosphere that fostered an egalitarian relationship between the researcher and the participants (Kirby & McKenna, 1989). Clandinin and Connelly (2004) similarly spoke about how in "narrative inquiry researchers need to deliberately imagine themselves as part of the inquiry" (p. 13). Sharing my own narratives as a means of empowering women to share their stories helped draw attention to the oppressive experiences of a community of women rarely given a voice (Hawa et al., 2017; Kteily-Hawa et al., 2018) and presented an opportunity to affirm the power of creative flexibility when implementing an emergent research design. In the disciplinary integration of health and adult education, this notion of community-engaged health research—that is, methods that allow for communities, researchers, and practitioners to learn together and from one another—has emerged as an important tool for deepening our understanding of adversity in underrepresented groups (Zieghan, 2012).

The terms *narrative* and *story* are often used interchangeably (see Frank, 2000), respecting that stories are "ways of thinking through the past, ways of making sense of ongoing situations

and guides for future action” (Mattingly & Garro, 2000, p. 17) and that a “narrative is something that is enacted in specific contexts and reflects culturally based constructive processes” (p. 16). Storytelling has long been an established means of cultural teaching, moral learning, and empowerment in South Asian communities (Davis, 2009). Many such cultures share a rich oral tradition that is entrenched in the South Asian diaspora (Garlough, 2013). In the context of HIV in particular, stories have the capacity to provide richer contexts to enhance a critical understanding of how complex social and economic conditions converge to produce and perpetuate HIV-related power imbalances and disparities. Narratives also generate a more holistic awareness of risk, choice, empathy, and stigma among women in marginalized communities (Larkey & Hecht, 2010). In research regarding HIV positivity in diaspora and minority women in particular, the literature has also consistently emphasized the importance of stories and the value of narrative as a means of communicating positive women’s experiences and transformations (Baumgartner, 2005).

Leggo (2008) spoke to the importance of “story, interpretation, [and] discourse” as the three tenets of narrative inquiry, specifying that discourse pertains “to the rhetoric of story-telling, the art and science of shaping and constructing a story for communicating to others” (p. 541). In Clandinin’s *Handbook of Narrative Inquiry*, de Mello (2007) indicated that arts-informed research can be defined as an approach where “art has been the way chosen to inform the analysis and the meaning made of the field text already existing,” as compared to arts-based research, where “art is applied as part of the method, as a way of composing and gathering field texts” (p. 214). In sharing my own experiences and reflecting on my discourse with the women subjects through the poetry of Mahmoud Darwish (2007) and literary criticism of Edward Saïd (2000a, 2000b), I nested my methodology with that of the arts-informed research discipline, aligning outcomes with a particular context (Eaves, 2014) of importance to diaspora health—that of South Asian immigrant women in the GTA who became infected with HIV in heterosexual relationships.

Framing the Stories as Illness Metaphors

I chose Frank’s (1995) illness framework as a powerful means of sharing the women’s narrated stories with other listeners—linking stories of restitution, chaos, and quest. Individuals who are ill can use narratives to understand and share their experiences with others. Their narratives are usually grounded in cultural understandings of what it means to live with and experience illness. Regardless of culture, however, illness can be viewed as the loss of both a life destination and map. People can use stories to help repair the damage caused by the illness (Ezzy, 2000; Frank, 1995). After analyzing and interpreting the member-checked interview data, I then privileged the women’s vetted voices while portraying their narratives using Frank’s illness framework, which resonated with my own experiences. This was acceptable in that narratives allow for multiple interpretations in terms of perspectives (Lindlof & Taylor, 2017).

In the *restitution* narrative, people’s actions are focused on getting well and being a good person, usually accepting their situation and fate. In the *chaos* narrative, “events are told as the storyteller experiences life: without sequence or causality” (Frank, 1995, p. 97). Narrators refuse to see life as ordered, which when combined with believing that the illness has no simple fix, leaves people marginalized. With the *quest* narrative, people “meet suffering head on; they accept [their] illness and seek to use it” (p. 115) by becoming

advocates and changing their lives. As moral agents, they speak of the ability to transcend the illness by moving beyond it to a new space and becoming someone new.

Shreya's Story (Restitution)

The meeting with Shreya took place in the living room at her comfortable and serene home. Shreya described herself as a South Asian Hindu woman in her 30s, born into a large wealthy extended family who lived in a small African city. Both her parents died when she was a child. She completed high school, worked in her family's businesses, then married at age 18.

My marriage was a love and an arranged marriage. After I became pregnant, my husband immigrated to Canada with plans for me to follow him the next year. My husband was working there. Yeah, it was the same year I got married. In the same year I had a baby. I had my daughter who passed away...from pneumonia...not sure...I came back to Canada. I got pregnant again. The doctor wanted to do all the tests because I was late [overdue] to have a baby. Yeah it was late. This is when I knew I was [HIV] positive. I didn't know there was a risk of my baby becoming infected with the virus. Actually the doctor told me towards, ah, 60 percent. I'll take the risk. Yeah my son is okay.

Shreya spoke about having HIV as part of her fate, one she accepts as part of her life. "I just feel like it's something normal like other people. I feel the same way. It's just that I have a virus." Shreya was surprised when questioned if it was her husband who had infected her. Her response was brief, indicating the role of religion in her life: "Ah, I don't know actually [chuckling]. Nobody usually asks me that question. I don't know. I guess I believe in God, yeah, so I'm not complaining. Actually I accepted it from the day one when I was told, yeah." Shreya's interpretation can be understood as a restitution narrative; she had accepted her situation and fate and was focused on getting well and on being a good woman.

Haifa's Story (Chaos)

Haifa is a woman in her 30s who was born in Africa. In addition to English, she speaks three African dialects. Several women helped her obtain the proper papers in her country of origin, accompanied her to Canada, and helped her connect with suitable social-services support through a church. Shortly after her arrival in Canada, she secured an apartment and a factory job working midnight shifts. Haifa stated that the decision to come to Canada was very difficult because she had to leave her family and did not know anyone in Canada. Meeting Haifa was difficult to schedule, because she was moving. After many phone calls and cancellations, I met Haifa and her little girl in the parking lot of a plaza. While a friend of hers looked after her daughter, we talked in my vehicle. Haifa was expressive and emotional throughout, not only about her diagnosis, but also about the multiple social stressors she was dealing with, including poverty, health, immigration, and housing.

I was going to college and so I was doing a little bit of bookkeeping. I didn't finish my college because...ummm...we were having problems in our country because we had a farm. My dad is white Christian; my mom is [South Asian] Hindu. Well they didn't get married actually. They just had a kid, so that's when the problems all came up. So when they grew

up, my dad never bothered us to go to church or anything...but my mom would always take us to the temple. So there's a conflict so they burned our farm and everything...when I came to Canada, I never knew where my family was. I was only 21.

Haifa reported that her family upbringing and culture dictated that she had to accept an arranged marriage. In spite of this, she engaged in a clandestine four-year sexual relationship with a man in her country of origin and described this as a love relationship. In Canada, Haifa met her husband at work and, after dating for six months, married him. Prompted by her immigration lawyer, Haifa had an HIV test and discovered she was HIV-positive. Haifa had had sex with only two men in her life: her boyfriend and her Canadian husband. She believes her husband is the one who infected her because her HIV test when she first arrived was negative. After telling her husband she was HIV-positive, he ended their relationship, despite him being HIV-positive. "I just happened to hear my co-workers talk, asking me, 'Are you HIV?' And I said, 'Who told you that?' But I would assume my husband is the one who told them." Haifa described the scene after her HIV disclosure:

When I told my husband, my husband packed his stuff without telling me and left. When I came back from work, he was gone.... The first time I found out I wanted to kill myself, especially when my husband left me without telling me he's going. I just had to walk into our house inside and your whole house is empty.

Her employer caused her further stress by changing her duties, leading Haifa to believe they wanted her to quit, so she did. Eventually, Haifa met another man who was South Asian and HIV-negative, and she had a daughter with him, born HIV-negative. She lived with this man, who was from a different cultural group than her own, which proved to be a problem for his family. Haifa and her boyfriend eventually broke up, but she and their daughter continue to have regular contact with him and he periodically brings them food and money.

"I'm on disability support now. I have a kid and most of the time I'm not doing well," she said. Haifa is currently looking to move outside Toronto to increase her anonymity as a woman living with HIV. She takes her daughter to a Hindu temple to calm her own mind and make social contacts. No one at the temple knows about Haifa's HIV status. She is in constant pursuit of stability and calm in her life. "I'm gonna give [my daughter] freedom. She can do whatever she wants to do. I want her to be free." It seems that Haifa is living the chaos narrative.

Anjali's Story (Quest)

Due to HIV-related illnesses and her travels, the meeting with Anjali took place after two months of phone calls and rescheduling. We met in her parents' comfortable home, with both of us sitting on her sofa bed in her basement apartment. Anjali, who is in her 40s, was confident, comfortable, and articulate throughout the interview process. She was born in an African country into a Muslim family consisting of two parents and her brother. In addition to English, she speaks four South Asian dialects. When her family first arrived in Canada, some relatives were already in the country and rented them an apartment that they moved into right away. Anjali described her upbringing as very traditional. "I was a very naïve

twelve-year-old....My brother was 11 and even going to school activities when we had trips. I was never allowed, yet he was allowed. He could go out, I couldn't go out."

Growing up, her social contacts were primarily with girls and boys she met at mosque, and school relations were often tense.

But growing up here was very difficult because there was a lot of discrimination with being a person of colour. I was brown so I was beat up, but then I beat them up too...we were foreigners in this new land and we were not white and we spoke with an accent at the time, so we were discriminated against, but in a couple of years, it didn't take long, cause kids blend in. Cause the only thing with Canada, it was the world, it was the land of all people. So it was, so I didn't feel "why did I come here," no.

While at university, she met her husband, a South Asian man from an African country who was in Canada on a student visa. At 26 years of age, she moved to her future husband's place of residence in Africa to marry him (after completing a university degree in Toronto and working for two years).

So, his family was very kind, but he was not kind. We had a lovely affair and romance, but after marriage he was just a terrible, terrible, terrible person. I felt like I was married just for a showpiece wife. And ah, yeah, it was emotional abuse...he was insecure, he was jealous, he was possessive. And the marriage didn't last. I've done lots of therapy to get him out of my system.

Anjali eventually left her husband and moved back to Canada to live with her parents. Upon her return to Toronto, she secured a stable government job. Later, through the experience of donating blood, she discovered from a phone call during her lunch break that she was HIV-positive. At the time, treatment options were scarce, and Anjali stopped working immediately and went on disability insurance through her work plan. She continues to live on disability as her health has slowly deteriorated and she experiences severe side effects from her HIV medications.

Reflecting on the role of religion in her life, Anjali said, "Religion plays a very large influence in our family, and me personally, I abandoned Islam for about 10 years or so, after HIV, and now I'm back with it and I find it very comforting to have religion back in my life." Anjali also disclosed her HIV situation to her nieces and nephews,

because kids are going to experiment in school whether you don't want them to or want them to. And when they do, it's better that they are prepared than in my case where I wasn't told about it. I would rather. So I always have told the children and cousins in the family, and the parents put me down. In fact, I'm protecting their children, because their kids are having sex, and I bring condoms and I gave condoms over the years to all the teenage kids.

She believed this approach could assist in confronting denial and result in people who do view themselves at risk subsequently protecting themselves during sexual activity. Anjali explained that the "best way in my view is more education and more real faces, because

people perceive HIV to be on the other side of the fence.” These life choices reflect the quest narrative, wherein Anjali is trying to be an advocate and transcend her HIV illness.

Locating Myself as a Researcher: Making a Safe Space to Tell Stories

I come from a religious Eastern-rite Catholic family, in which my mom was the spiritual matriarch. I went to church regularly when I was young, and I grew up with Eastern traditions that taught me to accept things that happened in my life as fate. As a result, Shreya’s story resonates with my strong feelings about the role of fate in my life and my acceptance of what God gave me, including my life in Canada. In a way, her story reflects the serenity in my life as described in the “Serenity Prayer”: “God grant me the serenity to accept the things I cannot change / ...Living one day at a time; / enjoying one moment at a time; / accepting hardships as the pathway to peace.”¹

Images of fire that burnt Haifa’s family farm are intertwined with images from my home country, fully engulfed with bombs and the feelings of dispossession that smothered me, not knowing where my family was when I first came to Canada as a refugee on my own. Haifa’s story mirrored the uncertainty of life for me as a newcomer who is completely uprooted. Both of us have this sense of loss as a result of experiencing different traditions and values and the absence of community support networks. I am still in pursuit of this never-ending journey of finding who I am and where I belong. I have always characterized my Canadian experience as being “out of place”—much like Saïd’s (2000a) experiences articulated in his memoir. And I still feel very much “in exile,” as Saïd (2000b, p. 173) expressed in his book, *Reflections on Exile and Other Essays*:

Exile is strangely compelling to think about, but terrible to experience. It is the unhealable rift forced between a human being and a native place, between the self and its true home: its essential sadness can never be surmounted. And while it is true that [one can have] heroic, romantic, glorious...episodes in an exile’s life, these are no more than efforts meant to overcome the crippling sorrow of estrangement. The achievements of exile are permanently undermined by the loss of something left behind forever.

Anjali’s story reflects the activist in me, where I feel fully engaged to initiate change and critically contribute to creating a space for discourse, acceptance, inclusion, equity, and action—currently essential drives in my life. I am heartened by the Palestinian poet Mahmoud Darwish (2007) and his poem “I Have a Seat in the Abandoned Theater,” in which he talks about taking a moral stand:

The actors were tearing up their scripts and searching for the author among us, we the witnesses sitting in our seats. I tell my neighbor the artist: Don’t draw your weapon, and wait, unless you’re the author!

—No

Then he asks me: And you are you the author?

1 R. Niebuhr (1892–1971), retrieved from <http://www.beliefnet.com/prayers/protestant/addiction/serenity-prayer.aspx>.

—No

So we sit scared. I say: Be a neutral hero to escape from an obvious fate

He says: No hero dies revered in the second scene. I will wait for the rest. Maybe I would revise one of the acts. And maybe I would mend what the iron has done to my brothers

So I say: It is you then?

He responds: You and I are two masked authors and two masked witnesses

I say: How is this my concern? I'm a spectator

He says: No spectators at chasm's door...and no one is neutral here. And you must choose your part in the end.

Conclusion

My personal and professional journey had an impact on my relationship with the women and ultimately my role as a researcher. Frank (2000) explained that "one person may be speaking, but stories are told with—not only to—listeners who are part of the storytelling" (p. 354). Some of the participants said they felt comfortable talking to me because of our shared experiences. Many participants believed that because I am an immigrant woman myself with diverse life experiences, even though I am not South Asian, I would understand their point of view and would not judge or look down on them. Positioning myself within the research was a key aspect of this art-making process because I was in a relationship with the participants, one that impacted the kinds of stories they were comfortable sharing.

Explaining how my perspective changed during my research constitutes an account of an artistic engagement, which de Mello (2007) argued is inherent in storytelling. Telling my own story of immigration, discrimination, and challenges of settlement appeared to create a safe space for women living with HIV to share their stories. I sought to convey these narratives of women who are living with HIV and are often voiceless. It raises the compelling issue of whose story is being told by whom. They told me their stories and I then recounted them in this article from a different perspective. In my case, adjusting the research design and acknowledging the power of Frank's (1995) illness narratives were significant parts of the arts-informed research process. Others engaging in similar research should remain cognizant of whose story is being told, by whom, and for what reason. It boils down to who gets to define what counts as art in a genre that is still emerging (Eaves, 2014).

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